

Transition in patients with childhood-onset epilepsy

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Valorisation

Globally about 15 million children suffer from epilepsy, and a considerable number of children continue to have lifelong seizures. In fact, epilepsy is the most common childhood-onset chronic condition transitioning into adulthood.¹⁻⁴ Past studies indicated that childhood-onset epilepsy transitioning into adulthood has a profound effect on the patients' long-term psychosocial outcome. Ongoing seizures and associated comorbid conditions, directly or indirectly, tend to impair the patient's perspectives for education, future employment, and social participation and relationships, as patients with epilepsy are often restricted in daily activities, e.g., in career and job opportunities, housing, driving license, and certain hobbies or social activities.⁵⁻⁷ Without a doubt, patients with epilepsy benefit from optimizing seizure control. However, several studies indicated that even patients with 'benign' childhood epilepsies with complete seizure remission during adolescence suffer long-term negative consequences of epilepsy, and have a psychosocial outcome which is far worse than that of a healthy control population.^{8,9}

With emerging adulthood, adolescents with chronic epilepsy have to undergo a transition from paediatric to adult health care. Epilepsy transition clinics have been described to ease such a transition.^{4,10-13} Since the first description of an epilepsy transition clinic in 1997⁴, interest in youth with epilepsy and the processes of transition gradually increased. However, still little quantitative data exists regarding transition outcomes.¹⁰ Furthermore, an epilepsy transition clinic is still not mentioned in the Dutch clinical guidelines.¹⁴

This thesis contributed to the improvement of transition for adolescents and young adults with epilepsy. More specifically, this thesis focused on the methods and process of epilepsy transitional care, on the psychosocial impact of epilepsy as a chronic neurologic condition transitioning into adulthood, on the short-term and the long-term effects of a transition intervention, and described the characteristics of adult patients with epilepsy who had a 'failed transition to independence'.

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Results and relevance

The results of this thesis contributed to improvement of epilepsy transitional care in several ways.

Literature review

The literature review in Chapter 2 made us aware of the fact that attention for epilepsy-related psychosocial issues is often inadequate or even absent compared to medical health care during the years of transition. Further, this chapter provided more insight in the patient-related factors (e.g., fear of leaving the familiar paediatrician)

and health-care-related factors (e.g., lack of preparation for transition in medical care) that block the improvement of the medical transition from paediatric to adult epilepsy care.¹⁵⁻¹⁷

Multidisciplinary epilepsy transition clinic with special attention for psychosocial issues

The multidisciplinary Kempenhaeghe Epilepsy Transition Clinic described in Chapter 3 has special attention for psychosocial care in adolescents with epilepsy during the years of transition. The aim of this multidisciplinary approach is not only to optimize seizure control, but also to provide adolescents and young adults with epilepsy with appropriate advice concerning typical age-related issues, e.g., in developing independence, social and societal participation and academic/vocational achievement. The rationale behind this multidisciplinary approach is to make patients and their caregivers aware of medical and specific developmental transitional problems in patients with chronic epilepsy, and to provide tailor-made advice, in order to improve their long-term medical and psychosocial outcome.

Risk factors for poor psychosocial outcome

The outcome of Chapter 4 helps to identify adolescents with epilepsy at risk for future adverse psychosocial outcome. The benefit of this study, compared to past studies, is that we focused only on adolescents and young adults in transition to adulthood, and that we paid special attention to specific transitional issues, e.g., self-esteem/independence, housing, study opportunities and employment. Hopefully, and ideally, early recognition of adolescents and young adults with epilepsy at risk for adverse psychosocial outcome can lead to early and precisely aimed interventions, and improve the chances and future perspectives of these patients.

Long-term effects of a multidisciplinary transition intervention

Chapter 5 revealed the long-term effects of a multidisciplinary transition intervention compared to patient-related intrinsic factors on the improvement in medical and psychosocial outcome after years of follow-up. Three previously defined transitional domains (medical, educational/occupational status and independence/separation/identity) were re-evaluated, and the psychosocial outcome of most of the patients had improved at follow-up. Compared to patient-related intrinsic factors, the transition interventions are a relative strong predictor of improvement in medical outcome, educational/vocational outcome, and improvement in the overall risk score after long-term follow-up.

Adults with epilepsy and a failed transition to independence

Chapter 6 of this thesis, showed that adults with epilepsy and a failed transition to independence experience more social loneliness and loneliness in general on the De Jong-Gierveld loneliness scale. Instead of taking advantage of still living with their parents, patients with a failed transition reported dissatisfaction with their current living situation and their social participation.

Summarized, this thesis provided more insight in the (lack of) general organization of transitional epilepsy care for adolescents and young adults with epilepsy, patients at risk for a future adverse psychosocial outcome, the results of a transition intervention, and the social participation and feelings of loneliness among adult patients with a failed transition to independence.

With the recent changes in the organization of the Dutch health care system, patients with epilepsy have to obtain funded resources and materials more frequently from local governmental organizations, e.g., local municipalities. This research program was funded by the province of Noord-Brabant (The Netherlands), with the idea in mind that further research and more insight in transitional problems might improve the psychosocial and societal functioning of patients with epilepsy. Improvement in societal participation and prevention of an adverse outcome might thereby decrease the pressure and demands on governmental health care programs and financial resources. Preferably, this might lead to decreased hospital (re)admissions, and a considerable reduction in health care costs on the long-term.¹⁸

Target groups

The main goal of our research was to optimize transitional care for youth with chronic epilepsy in order to improve their long-term medical and psychosocial outcome (e.g., participation, future career opportunities). Except for patients with epilepsy and their relatives, the results of this thesis are especially of interest for medical health care workers involved in adolescents with epilepsy during the transition from paediatric to adult care. Involved health care workers may include pediatricians, neurologists, general practitioners, nurse specialists, neuropsychologists, educationalists and social workers. Further, with the development of future career opportunities, social networks and friendships, the results of this thesis might also be of interest for teachers and employers of adolescents with chronic childhood-onset epilepsy.

Innovation

In the last two decades the medical transition process of youth with chronic conditions received more attention. However, evidence was clearly lacking for patients with chronic childhood-epilepsy compared to other chronic illnesses. The results of this thesis contributed to the knowledge of multidisciplinary transitional care for adolescents with epilepsy, patients with epilepsy at risk for a poor psychosocial outcome and the long-term effects of a transition intervention. Further, we gained more insight in the functioning and social participation and feelings of loneliness among adults with epilepsy and a failed transition to independence.

Implementation

The results of this thesis can be used to ease the medical transition from paediatric to adult health care for adolescents with epilepsy during the years of transition. To implement transition clinics for adolescents and young adults with epilepsy, it is recommendable that pediatricians and adult neurologists/epileptologists work closely together.

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